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ABSTRACT

Intended as an introduction to mental retardation, the booklet provides information on definitions, incidence, etiology, diagnostic tests, developmental characteristics of persons with varying degrees of retardation, habilitation services (such as community programs, residential care and special education), and preventive measures. (CL)

The Problem of Mental Retardation

U.S. DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE
Office of the Secretary
Office for Handicapped Individuals
in cooperation with
The President's Committee on Mental Retardation
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FOREWORD

Mental retardation is a problem not just for people who are retarded. It touches the lives of all of us.

When a child is humiliated by a label that sets him apart from other children, when a youngster cannot understand what comes naturally to others his age, when an adult is forced into dependency because he cannot earn a living, we are all affected.

We pay the price by sharing in the suffering, both emotionally and economically. Because mental retardation is an intricate problem that cuts across the spectrum of responsibilities of the Department of Health, Education, and Welfare, the solutions require a concerted effort for effective planning and coordination.

We all share in the responsibility to prevent the condition, to lessen the disability, and to help people who are retarded to lead more independent and productive lives.

This booklet is intended as at least an introduction to understanding mental retardation, why it exists, and what can be and is being done about it. An informed citizenry is the first requirement for effective action.

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Assistant Secretary for
Human Development

People Who Are Mentally Retarded

. . . are limited in their ability to learn and are generally socially immature. Some are further handicapped by emotional and physical disabilities.

In more scientific terms, "Mental retardation refers to significantly subaverage general intellectual functioning existing concurrently with deficits in adaptive behavior and manifested during the developmental period." [1]

Among the many causes of mental retardation are: genetic and chemical abnormalities, deprivation in early childhood, damage to the central nervous system, toxic agents (such as lead), viruses, or brain injury early in life. Premature infants are especially vulnerable, as are children born to women over 35.

Estimates reveal that about 6 million persons in the United States—or roughly 3 percent of the population—are mentally retarded. This condition causes more disability among children than any other physical or mental abnormality. There are differences among retarded people, just as there are among the rest of the population.

Generally, those whose Intelligence Quotient (IQ) is 50 or above are capable of being educated for a relatively independent life. People whose intellectual capacity and social maturity place them in the severely and profoundly retarded range require more sheltered environments.

[1] *Manual on Terminology and Classification in Mental Retardation,* American Association on Mental Deficiency, Washington, D. C., 1973 edition.

However, all but a small percentage can gain some measure of independence if given adequate help. The amount of independence each achieves depends in large measure on the quality of care and understanding he receives and the degree to which these relate to his needs.

Estimated Distribution of Retarded Persons in the United States by Age and Degree of Retardation[2]

Degree of Retardation	All Ages		Age by Years	
	Number	Percent	Under 20	20 and Over
Total	6,000,000	100.0	2,454,000	3,546,000
Mild (IQ 52-67)	5,340,000	89.0	2,136,000	3,204,000
(Moderate) (IQ 36-51)	360,000	6.0	154,000	206,000
Severe (IQ 20-35)	210,000	3.5	105,000	105,000
Profound (IQ 20-0)	90,000	1.5	52,900	37,100

[2] Adapted from data in *Facts on Mental Retardation*, p. 15, National Association for Retarded Children, Inc., New York City, 1963.

This care must start in the earliest years. Studies indicate that approximately 50 percent of an individual's intellectual development takes place between conception and age 4; about 30 percent between ages 4 and 8. The period encompassing gestation and early childhood determines to a large extent the life adjustment potential for all individuals, on all intellectual levels.

Among the many factors playing a part in each child's development are heredity, nutrition, and his living conditions, emotions, physical factors, inter-personal relationships, and the interaction between the individual and his environment.

When something goes wrong — either through human neglect, an error of nature, or an environment which has failed to provide opportunities for healthy emotional and

mental growth—retardation can be the result.

Although this problem is found in families of all income levels, by far the largest number of mentally retarded children are born to parents in poverty. The type of retardation that results from social and cultural deprivation is often mild, or "borderline," and may not be readily recognizable until the child enters school. There, such children are seen to perform below the levels of achievement normally expected of youngsters their age. Achievement, however, is determined largely by the social, educational, and cultural standards of the community. Thus, a person with limited abilities may function adequately in menial work on a farm but not be able to meet the demands of crowded, complex, and competitive life in a city.

Retarded children from deprived environments, if given adequate early help, often can improve their school performance. However, this improvement may not be sustained without follow-up. In the absence of early intervention and a continuous follow-up program, retarded children living in conditions that stunt mental and social growth tend to drop to even lower IQ levels as they grow older.

Many pre-school programs and projects such as Head Start are designed to provide such children with early stimulation to offset the negative environment. These programs are based on the belief that retardation due to deprivation is not only reversible, but preventable through changes in the society which contributes so heavily to its occurrence. They often do provide a real "head start" in life.

Unlike retardation due to deprivation, retardation due to biological or organic causes, generally may not be reversed. Identified causes include genetic or metabolic defects, diseases, injuries at birth or brain injury resulting from an accident in childhood. Most of these children have physical as well as mental handicaps, and usually they are among the more seriously disabled.

Tests to Determine Mental Retardation

. . . range from chromosomal analysis to intelligence and social adaptability tests of school children.

Many States require screening tests for infants soon after birth to detect chemical and neurological abnormalities which can result in retardation. In these cases, immediate treatment sometimes can prevent retardation from developing.

As the infant grows older, sensory and motor development, along with perception, can be measured even while the child is still very young.

Later, the so-called "IQ tests" are given. Intelligence is generally defined as problem-solving ability; ability to adapt appropriately to environmental demands, and ability to apprehend abstract interrelationships.

Another important dimension in the determination of intelligence is adaptive behavior. Adaptive behavior refers primarily to the effectiveness with which the individual copes with the natural and social demands of his environment. (See table on page 5)

The result of an intelligence test alone is insufficient evidence of retardation, since intelligence is not constant, but relatively variable, and subject to emotional and environmental influences.

If considered along with other test results, however, the IQ can be an important factor in determining a child's potential for learning. If an IQ of 100 is considered as normal for the average person, then an IQ of 40 indicates that the individual at the time of testing shows a potential for performance of 40 percent of normal. (See chart on page 5)

Adaptive behavior classification for the retarded is rated on the following basis:

Mild:	Development slow. Children capable of being educated ("educable") within limits. Adults, with training, can work in competitive employment. Able to live independent lives.
Moderate:	Slow in their development, but able to learn to care for themselves. Children capable of being trained (termed "trainable"). Adults need to work and live in sheltered environment.
Severe:	Motor development, speech and language are retarded. Not completely dependent. Often, but not always, physically handicapped.
Profound:	Need constant care or supervision for survival. Gross impairment in physical coordination and sensory development. Often physically handicapped.

Today, much effort is going into redesigning intelligence tests to insure that they make adequate allowance for cultural differences. This would permit a greater degree of accuracy in test results.

Consideration is also being given to development and standardization of tests of social competency—since this plays an equally important role in establishing the presence or absence of mental retardation.

All tests must be administered with great care. There is, for example, the danger of a diagnosis of mental retardation in a young child whose problem may stem from impaired hearing or vision.

Mild	IQ 52-67
Moderate	IQ 36-51
Severe	IQ 20-35
Profound	IQ Less than 20

Though mentally retarded people often have poor muscular coordination, speech and hearing problems, poor vision, difficulty in perception, extreme lethargy or hyperactivity, each of these conditions can be present without mental retardation.

Thus, diagnosis and evaluation is extremely difficult and should be conducted by a team of specialists in several disciplines. Most reliable is a comprehensive mental retardation clinic which offers medical, psychological, social and educational examinations.

The Deprived Child

. . . who is retarded due to non-organic causes may never receive the benefits of special education or rehabilitation. His problem may not be recognized until it becomes apparent that he cannot keep up with the rest of his class in school.

He may then fall into a cycle of failure which further limits his ability to learn. Dropping out of school at age 15 or 16, he faces a future with no skills and, too often, becomes a social problem.

On the other hand, if the very young deprived child and his parents—especially the mother—can participate in a child development program, such as Home Start, chances are good for overcoming the deficit, and avoiding retardation. Some may require special education for specific problems, but with special precautions against mislabeling the child retarded.

In the mass migration to cities that has occurred in the last decade, thousands of children in low-income families have been transplanted from one culture to an entirely different one. Many have been found "subnormal" when measured against unfamiliar norms.

These children come from ghost towns in Appalachia, rural Puerto Rico, sharecropper farms in the deep south, and tarpaper shacks from all over the country.

Those native to inner-city slums are crowded into even more unsatisfactory living conditions by the daily waves of new arrivals. They are often hungry, neglected and suffering from chronic anxiety.

Opinions vary widely on the causes and solutions to educational and social problems these children experience. It has been pointed out that many speak a different "language" from that of the usual textbook and classroom.

Increasingly, educators see the need for early childhood enrichment, training mothers, and revising curricula to meet the unique needs of deprived children. In addition, they recommend changes in total life patterns for these children and their families.

Mental Illness

. . . is not the same as mental retardation. They are separate and distinct conditions. Mental illness is often temporary and may strike at any time during the life of the individual. Mental illness can be treated and often cured.

Mental retardation, on the other hand, occurs during the period of development, or is present from birth or early childhood. It may be alleviated through medical treatment, special education, training, rehabilitation and proper care, but it cannot be "cured."

When retarded individuals have difficulty adjusting to the demands of society, the problem is usually related to limited intellectual capacity, and an inability to understand what society expects of its members. When mentally ill persons fail to adjust to society's demands, it is often because their mental disorders have caused them to lose touch with reality, or their emotions interfere with so-called normal responses.

However, the mentally retarded also may have emotional problems; they can become mentally ill through frustration born of repeated failures, the humiliation of being ridiculed and the fears that come from trying to

Developmental Characteristics

Degrees of Mental Retardation	Pre-School Age 0-5 Maturation and Development	S Trai
Mild	Can develop social and communication skills; minimal retardation in sensorimotor areas; often not distinguished from normal until later age.	Can le skills u sixth g teens. toward "Educ
Moderate	Can talk or learn to communicate; poor social awareness; fair motor development; profits from training in self-help; can be managed with moderate supervision.	Can pr in soci tional progre grade subjec travel places.
Severe	Poor motor development; speech is minimal; generally unable to profit from training in self-help; little or no communication skills.	Can tal commu trained health from s trainin
Profound	Gross retardation; minimal capacity for functioning in sensorimotor areas; needs nursing care.	Some r presen minim ing in s

of Mentally Retarded Persons

School Age 6-20 ning and Education	Adult 21 and Over Social and Vocational Adequacy
rn academic p to approximately ade level by late Can be guided social conformity. ble"	Can usually achieve social and vocational skills adequate to minimum self-support but may need guidance and assistance when under unusual social or economic stress.
fit from training l and occupa- kills; unlikely to s beyond second evel in academic s; may learn to lone in familiar	May achieve self-maintenance in unskilled or semi-skilled work under sheltered conditions; needs supervision and guidance when under mild social or economic stress.
k or learn to nicate; can be in elemental habits; profits stematic habit g.	May contribute partially to self-maintenance under complete supervision; can develop self-protection skills to a minimal useful level in controlled environment.
notor development ; may respond to l or limited train- elf-help.	Some motor and speech development; may achieve very limited self-care; needs nursing care.

survive in a highly complex and somewhat impersonal world.

Parents can contribute to frustrations by overprotectiveness which keeps retarded children dependent. Or parents may be overambitious, pushing their children beyond their intellectual and emotional capacities.

Community Services

. . . can often eliminate the need for long-term residential care. Among such community services are: diagnostic and evaluation clinics; early childhood education facilities, training and enrichment programs; day-care centers; pre-school and Head Start projects with follow-through; special tutoring; quality special education; summer camps and recreational facilities; group living arrangements in the community; vocational training; rehabilitation programs; sheltered workshops; employment opportunities; and "surrogate parents" or guardianship arrangements for older retarded persons. The optimum is a complete plan of life-time protective services available as needed.

Sheltered homes or part-time residential care can be effective in giving temporary relief to parents of a retarded child who lives at home.

Parent counseling services are an additional aid, especially during crisis periods: the discovery of the condition, the beginning of schooling, adolescence, the first years of adulthood, and when the parents reach the age when they can no longer care for the child—either because of their advancing years or the condition of the child.

All of these services offer alternatives to institutional placement, or can be provided as part of the therapeutic program of residential facilities.

Whether at home or in residential care, retarded persons grow up. Their needs follow the pattern of all human beings, though in a different degree. For example, it is as natural

for a retarded adolescent to want to cut parental ties as it is for any other young person. Community group homes can provide this opportunity while still offering necessary protection and supervision.

Retarded persons need close personal friends outside the family; they need a group to belong to, outlets for their energies, and identity. Such community activities as Scouting, camping, competitive sports, religious affiliations, social groups, accessible shops, and transportation can contribute much toward a retarded person's sense of well being and belonging. Similarly, a job to go to and money to spend are as essential to the self-respect of the retarded adult as to any other.

The community can provide these opportunities—at a cost far less than that of a lifetime in an institution—if enough people care enough to make it possible. The American taxpayers contribute over a half-billion dollars a year to operate public facilities for retarded people.

In the long run it costs less to do it right—both in terms of human lives and tax dollars.

Manpower

. . . of both the professional and supportive type is in short supply. Despite Federal training grants, there is great need for more special education teachers, psychologists, social workers, physicians, therapists, counselors, recreation specialists, and capable administrators to direct programs for retarded children.

It is imperative to tap the vast resource of allied personnel who can be trained to relieve the professionals of many duties they now perform which do not require professional expertise.

There is also a growing awareness of the effectiveness of trained volunteers, especially young people. Volunteer work has served as a gateway to careers in this field for many of all ages.

Residential Care

. . . is often a necessity for the more severely retarded who need constant attention, and for older retarded persons left with no one to care for them. There are now approximately 175,000 residents in state institutions for the retarded in the U.S.

Some residential facilities are outstanding and offer good programs in special education and training, medical care, therapy and recreation—sometimes coordinated with community activities and services. Other residential facilities may be limited to providing little more than basic subsistence.

Even profoundly retarded persons respond favorably to pleasant, colorful, and personalized surroundings. Architecture and interior decor are important parts of the whole therapeutic program; of even greater importance is the healing effect of a person who cares.

Recently implemented behavioral modification techniques are proving that nearly all retarded people can be trained to care for their personal needs, such as self-feeding, dressing and toileting. Many thought to be "hopeless cases" are now being trained in self-care and returned to their homes for visits. Some are living in group homes.

The best kind of residential care seems to be that most closely resembling family life—a small group or unit, with "parents" to look after the residents, and professional help as a resource when needed.

Some very successful group homes are located in apartments or individual houses scattered throughout the community.

Special Education

. . . is one of the most important means to the goal of productive citizenship and self sufficiency for the retarded.

Although classes for children who are retarded are now offered in every State and are

growing in number, there is a critical need for many more. Current estimates indicate that not more than 60% of all retarded children in *any* State are being provided special educational services.

Effective special education is oriented toward the practical goal of independent and productive living, so that the student can graduate into the kind of job he can do, with preparation for handling money, the ability to use public transportation, and a well developed level of social competency.

Many schools integrate the children from special education classes with those in the regular program for such subjects as art, music, physical education, industrial arts, and home economics, bringing them into the center of school life as far as feasible. However, physical integration alone does not guarantee acceptance by non-retarded youngsters. Psychological integration is also important and requires considerable planning by school officials and related personnel to be effective.

A Federal law that was passed in 1968 provides authority for broadening efforts in vocational education of the handicapped to include the mentally retarded. This program should have a significant impact on vocational training of retarded children within the school system.

Individually prescribed instruction is proving highly successful in those schools which have the capability for it. This is programmed learning which allows each child to progress at his own pace while the teacher acts as a guide and resource person.

Rehabilitation

. . . for retarded persons can be the passport for entrance into the life of the community.

The most effective rehabilitation services provide training in job skills as well as practical preparation for independent or semi-independent living.

In some cases, training is an extension of

a special education program geared to productive living from the start. In others, rehabilitation services make it possible for older, long-term residents of institutions to move out into the community and take jobs.

Coordination is needed in each of the steps along the way: special education, vocational training, rehabilitation, arrangements for community living, and employment. Employers need preparation for the kinds of supervision retarded workers require, and necessary patience and understanding. They must be provided with a clear picture of the strengths as well as the weaknesses of their retarded employees.

Increasingly, employers are learning to appreciate the reliability of the retarded worker, his punctuality, and his contentment with the kind of work that causes high turnover among more skilled employees.

Thousands of retarded people are now being trained to fill many jobs that require such attributes. There are just as many of these jobs that need to be filled—the biggest problem is getting the two together. There has been a great deal of progress in job placement of the retarded individual in the last few years.

Preventive Measures

Medical care throughout pregnancy to lessen the risk of untreated and unsuspected infections, diabetes, and other diseases, as well as to help prevent premature births—a major cause of mental retardation.

Availability of education and health services for every child from birth.

Expansion of maternal and child health programs.

Establishment of urban and rural community health and education centers for preventive health care and screening, plus early education, day care, and social services.

Expansion of career planning in supportive

health, education, and social services to serve in low-income areas.

Expansion of programs that train and assist parents in their role as the primary educators of their children.

Development of large-scale voluntary service programs especially for youth organizations in poverty areas.

Availability of family planning information to all who desire it.

Stimulation of intensified research into the causes of mental retardation—those associated with social and cultural deprivation, as well as those of biological origin.

Immunization against German measles (Rubella).

Avoidance of all drugs during pregnancy except those prescribed by a physician.

Genetic counseling if the family history includes abnormalities, or if the mother is over 35.

Vaccination against 10-day measles for each child.

Immediate treatment for venereal disease.

Prenatal tests for incompatible blood factors.

A balanced diet for children and adults.

Limitation of radiation exposure for both parents before conception and for mothers during pregnancy.

Thorough medical examination of the newborn.

Research has now produced a rubella vaccine which has the potential to protect against the 3-day German measles, a frequent cause of defects if contracted by the mother especially during the first trimester of pregnancy. The answers are yet to come on the prevention of certain infectious diseases and virus disorders that cause retardation, problems caused by prematurity or birth injury, prolonged high fever, and toxic agents.

Progress is being made in genetic and molecular biology, which will help provide some of the answers to the causes of biological mental retardation.

Practical Application

. . . of all preventive and remedial measures known, however, is still a distant goal, especially for those who need it most.

Application of this knowledge could significantly reduce the incidence of mental retardation, and make life a more satisfying

experience for the majority of those who are retarded.

National Concern

As one would expect, the first to be concerned about the problem of mental retardation were the parents of afflicted children. The first counselors were the physicians attending these children and families. As the ranks of concerned people grew, they began to include others—from the professions, foundations (public and private), legislators and representatives of Government agencies who were becoming convinced of the urgent need for action in this area.

In 1961, a panel of experts was appointed by the President to study the problem and to draw up a plan of action. One year later the group published a comprehensive report entitled "A Proposed Program for National Action to Combat Mental Retardation." A followup White House Conference was held to acquaint the States with the proposals.

Significant Federal legislation enacted since the Report of the President's Panel on Mental Retardation reflects increased mental retardation programming in areas involving the provision of services, construction of facilities, research training, and planning. Under this legislation, Federal resources stimulate action by State and local governments and private groups.

In May 1966, the President's Committee on Mental Retardation was established to:

. . . advise the President on what is being done for the mentally retarded;

. . . recommend Federal action where needed;

. . . promote coordination and cooperation among public and private agencies;

. . . stimulate individual and group action;

. . . promote public understanding.

Coordinated national and local efforts as well as individual contributions are important in helping mentally retarded persons take their rightful place in the world.

Such concerted efforts can improve the quality of life for approximately 6 million retarded persons and transform most into productive citizens. Concern for retarded people clearly becomes an investment in human worth that pays dividends to every citizen of the nation.